DOCUMENT RESUME

ED 330 186 EC 300 158

AUTHOR Brodin, Jane
TITLE Communication in Profoundly Mentally Retarded and Multiply Handicapped Children.
SPONS AGENCY Swedish Council for Planning and Coordination of Research.
PUB DATE Aug 90
NOTE 10p.; Paper presented at the International ISAAC Conference on Augmentative and Alternative Communication (4th, Stockholm, Sweden, August 12-16, 1990). This project was also supported by the Swedish State Inheritance Fund.
PUB TYPE Speeches/Conference Papers (150)

EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS Body Language; Case Studies; Communication Skills; Foreign Countries; Males; Multiple Disabilities; *Nonverbal Communication; Parent Child Relationship; *Severe Mental Retardation; Time Factors (Learning)
IDENTIFIERS Sweden

ABSTRACT

The paper reports on a project which examined the communication of a 10-year-old Swedish boy with severe retardation and multiple disabilities. Interviews, observations, and videorecordings were used. Communication categories included body language, gestures, head position, gaze/eye contact, and sound/mouth and tongue use. The child was found to communicate with gestures and body language and to have no understanding of pictures or symbols. Interaction patterns were identified from the videofilming technique and include patterns typical of newborn infants, including caregiver initiation, child orientation, and child motor activity. The child's need for plenty of time to absorb input was noted. Includes 10 references. (DB)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

Jane Brodin
Department of Education
Stockholm University
S-106 91 Stockholm
Sweden

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)
This document has been reproduced as received from the person or organization originating it.
Minor changes have been made to improve reproduction quality.
Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

ED330186

COMMUNICATION IN PROFOUNDLY MENTALLY RETARDED AND MULTIPLY HANDICAPPED CHILDREN

Paper presented at The Fourth International ISAAC Conference on Augmentative and Alternative Communication in Stockholm, August 12-16, 1990

Jane Brodin

BEST COPY AVAILABLE

"PERMISSION TO REPRODUCE THIS MATERIAL HAS BEEN GRANTED BY
Jane Brodin
TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

The project has been supported by The Swedish Council for Planning and Coordination of Research and The Swedish State Inheritance Fund.

Jane Brodin
Department of Education
Stockholm University
S-106 91 Stockholm

COMMUNICATION IN PROFOUNDLY MENTALLY RETARDED AND MULTIPLY HANDICAPPED CHILDREN, Paper presented at the Fourth International ISAAC Conference on Augmentative and Alternative Communication, Stockholm, August 12-16th, 1990.

Today most Swedish children with disabilities live at home together with their parents. One goal in the Swedish handicap policy is to abolish all the institutions in accordance with the social welfare legislation and the special legislation for the mentally retarded. The Social Act of 1982 has assumed the form of a goal-oriented enabling act. Within the framework of this enabling act, municipalities may organize the services offered according to their own conditions and requirements. As a result of the abolition of the institutions also for the most severely handicapped, families with children with disabilities need an increasing amount of qualified support. In our country we have a social system that gives families with disabled children legal rights to obtain services from society.

In Sweden there are today about 3.000 profoundly mentally retarded children below the age of 19. Most of these children have multiple handicaps and many have three, four or even more additional handicaps. A great number of the profoundly mentally retarded children are visually impaired, hearing impaired, physically disabled, incontinent, have epilepsy and severe speech and communication disorders. These children are at an early stage of development and need a lot of assistance in their daily living. They are diagnosed and assessed to have an IQ below 10 which means that they are profoundly mentally retarded.

In 1985 I started a research project of the play situation of profoundly mentally retarded children from a parental viewpoint (Brodin, 1985). The subject was originally initiated by parents and playing was presented to me as a big problem for these parents. My original intention was to find out how these children play, what kind of material they prefer to play with and what problems the parents have to face with regard to the play situation. The study was based on questionnaires and interviews with 38 families with severely disabled children ranging from 2 to 26 years old. One might think that at the age of 26, a person is no longer a child, but in order to meet the wishes of her parents, I decided not to exclude this young woman from the study. The results of this study show that

these children in general are very passive, they take few or no initiatives themselves and have a very short attention span. They often simply sit still and watch, waiting for someone else to start up an activity or getting them involved in something. They have poor social skills and don't interact with others spontaneously.

These children do not play with conventional toys although every child has one or two favorite play things such as a paper bag, a kitchen tool etc. to handle. They all, however, enjoy playing with things that stimulate their visual and auditory senses. One problem was that the parents did not identify or accept these activities as play, their concept of play being based on their own experiences and what they can find in the toy stores. Another problem was that the children were not accepted as play mates because they had not learnt the rules for social interaction. Its evident that the concept "play is essential for all children" must be discussed further. Most importantly, in my opinion play gives the child new experiences and opportunities to communicate and every child needs help and stimulation to develop (Brodin, 1987; Nielsen, 1988). In research and other literature about children with disabilities play often serves the purpose of training different functions in order to improve them - in other words : " training in order to become similar to other children". This study also focussed on another problem : the role of communicative interaction in play.

If a child has no speech and is at an early cognitive level of development, playing is perhaps the only way to reach the child. If a child does not respond , it is necessary to keep trying as children with severe disabilities need plenty of time to produce a response. They often have very weak signals which are difficult to notice and to interpret and If we fail to see these signals and do not give the child an adequate feedback, he will finally give up and cease to make any signals at all.

My interests, therefore turned to the area of interaction and I'm concentrating present research on finding out how play can be used as means of communication and how parents can be encouraged to continue to play and communicate with a child who is not responding.

THE AIMS OF THE PROJECT

The aim of my research has thus been changed and developed. The overall purpose is to increase the understanding and knowledge of severely handicapped children and their parents. The aims are thus

* to **describe interaction** between mothers /caregivers and their children with multiple handicaps
* to find **methods for analyzing and interpreting** videotaped observations of non-verbal communication.

A pilot study of a ten year old boy called Peter was completed. I followed him with a videocamera during some days in order to describe his ways of communication. Furthermore the play and communication of six profoundly retarded children with multiple handicaps have been studied in the form of case studies. The age of the children range between 1 and 10 but their developmental levels are below the age of one according to test results .

METHODS

My study is **descriptive, mainly qualitative** and **longitudinal.** The data collection is based on:

- **Interviews** with parents och preschool/school teachers with structured questions. Notes are taken at the time and place of the interviews.
- **Unstructured questions** from ordinary conversation in the child's home and at school
- **Observations** (natural and videotaped)
  Natural observations. Notes are taken during the visit and immediately after leaving the childs home.
  Videotaped observations (20-40 minutes each time) at 5-6 different occasions with about 1-2 months between visits depending on the childs physical health.

The emphirical datas are collected from three different sources (parents, teachers and researchers perspective). The datas are aslo collected with three different techniques (interviews, unstructures questions and observations). This method has been named triangulation in literature (Patton, 1980) and it is usually used by socialantro- pologues.

The two situations chosen are: **playtime** with mother/caregiver and **meals**

The notes from the inverviews have been checked and approved by the parents in order to avoid any misunderstandings but there is also or perhaps more a question of ethics. I'm not interested in using information which can in any way hurt and negatively influence the situation of the family. As I have given the families the opportunity to read and a accept the material I intend to use , they feel free to speak in a more spontaneous way and without anger. After all, the parents have not asked me to exclude anything from the material which I consider as valuable. What I mean with valuabel can of course be discussed but there are only some points which they have asked me to exclude that can be interpreted negatively with regard to their child. I have found that piece of information of no specific value for the results of the study. I have analized and interpreted the videofilms and used a particurlarly elaborated and detailed way

of transcribing . Afterwards the films have been checked and interpreted by the parents, a method I have chosen to call "double checking". This second analysis is done in order to avoid misunderstandings and inadequate interpretations. This method, however, is very time consuming. It's necessary however, to point out that it's not always possible to make the same interpretation, as parents and researchers have different perspectives which produce the opportunity to see matters from various viewpoints.

Examples of Categories that can be found

How is communication analysed and interpreted? The main principles for analysing interaction with severely disabled children are to look carefully and systematically at the following aspects:

- **body language** (breathing, position of the body etc)
- **gestures** (turning the body towards and away from, streching for things, arm movements etc)
- **head position** (turning head towards and away, raising head, nodding, bending down
- **gaze/eye contact** (looking at objects/persons, following with eyes, looking on the sly etc)
- **sound/mouth and tongue** (opening mouth, laughing, smiling, grumbling, squeaking, sucking the tongue etc)

Methodological problems:

- One can never be sure that one has interpreted a child correctly
- It's difficult to know for sure whether the communication is intentional or not
- Mothers often interpret their children "as if" their children mean something special
- There is always a risk for "over-interpretation"
- It's also difficult to decide whether the child is taking his turn or not in communication especially as the child is often interrupted
- The severely disabled child needs more time to interact and to respond (Kylén, 1981; Nielsen, 1988; Brodin, 1989)

According to Light (1987) the communicative competence in a child depends on the physical, emotional, social and cognitive ability of the child as well as on the social environment. If the facilitators act in an encouraging way it seems as if the child will increase his attempts to communicate.

The case studies of six children with multiple disabilities will give me an opportunity to find out if it's possibile to make generalisations. Although, it's a

bit early to say yet, it appears that each child has his own pattern of interaction but some similarities between children can be seen.

A CASE STUDY

I will now introduce Peter in order to give you an idea of my work.

Name	Peter
Age	10 years old
Environment	Home, with parents and two siblings (a sister of 4 and a brother of 14)
	Special school, training class with 3 other pupils
Diagnosis	brain damage
Status	profoundly mentally retarded
	severly motor disabled
	speech/communication disorders
	incontinent
	epilepsy
	good head control, no body control
	dependant in all activities
	no functional vision, but no deficiency
	normal hearing
Communication	non-verbal
	gestures, body language
	natural reactions and signals

Summary Peter.

Peter is a ten year old boy living with his parents and two siblings in a house outside Stockholm. He attends a special school with only a few pupils in each class. He has a personal assistant who takes care of him at school and gives him sensory stimulation and training in daily living for example communication. Peter has a brain damage due to a virus infection during the pregnancy. He is profoundly mentally retarded and has many additional handicaps. Peter is severely motor disabled, has speech and communication disorders, is incontinent and has epilepsy. He has good head control but no body control. He does not use his visual sense in a functional way but there is no physical deficiency in his eyes. Peter cannot sit unsupported and he cannot stand up. He eats mashed food and wears diapers.

Peter communicates with gestures and body language. He uses natural reactions and signals for his communication (Kylén et al, 1983). He does not understand pictures or symbols.

When I first met Peter, four years ago, he was a very dissatisfied child. Today he is happy and his personal assistant thinks that this depends on the fact that he is more communicative and more interested in people and things in his environment.

In order to understand Peter and to know what he wants it is necessary to interpret his signals. Peter uses a special pattern for interaction which has been repeated in several sequences in the videofilms:

1. When you talk to Peter and joke with him he gets happy and exhilarated
2. Peter smiles and looks satisfied, he starts waving his arms intensively
   His motoric activity increases.
3. Peter begins to make moves with his mouth and sucks his tongue.
4. He moves his hands up to his face and puts one or two fingers into his mouth and starts to suck on them.
5. After a short while he bows his head, lowers his eyes and sits quitly and silently - he doesn't make a sound or a movement.

The same pattern that Peter shows has been described by Holmlund (1985), in her studies of newborn infants and their ability to imitate. She has shown the same results as Trevarthen (1988) did with children of 14 days. Holmlund is now doing research with Baldwin's circular theory and she describes the early interaction pattern as follows:

1. The first phase contains Initiation. The mother initiates communication with the child by talking, smiling, singing and touching
2. The second phase is called orientation. The child orientates against the mother by turning his face to his mother and looks at her
3. The third face is motor activity. The child turns his face and looks away from the mother and a motor activity starts

Holmlund has arrived at the opinion that this is the base for development of all human interaction and turntaking in communication. She has also found that a great deal of Piaget's theoretical points originiated from Baldwins theory. Piaget also refers to Baldwin in his reports.

Returning to Peter, I shall point out some problems in his pattern of interaction. One problem is that the silence often is broken by someone coming into the room talking to Peter about a different topic. He probably needs arelatively long uninterrupted period of silence to absorb new information. The best way to help him to interact is to give him lots of time

but unfortunately there are often interruptions and disturbances interferring with the process of learning to interact.

When Peter eats he wants to be fed by his mother. He looks at her and smiles. If Peters father takes over the feeding, he starts to cry. He is most unhappy and screams until his mother arrives. This happens everytime they try to change the routines and it is important to show Peter that his parents understand him why he is upset. As soon as his mother takes over he is happy again.

Another example. Peter sits in his armchair and his little four year old sister stands by his side. She wants to play with him but he is not interested. He turns his head away from her but quickly she runs over to the other side. He brings his hand up to his head, lower his head and and turns it away again. As soon as he notices his sister he turns his head back again. He is not interested and this message can be read very clear from his face. If he could, he would probably have said "no - please leave me alone" (his mothers' interpretation). His signals in this situation are very clear indeed.

Peter loves it when his mother gives him a shower and gives him a massage. This is one situation where Peter's communication is functioning the best. This is also the only time when he "tells" his mother that he wants to have more. I earlier thought that it was important for severely disabled children to be able to say "yes" and "no," but today I don't want to call that communication any more. Peter lifts his head, turns it to his mother and looks at her. If he could he would probably have said "Give me more please". His mother understands and this is communication . However there is a risk as other people do not always understand him.

There are many problems in studying communication in profoundly mentally retarded and children with multiple handicaps.

- One can never be quite sure of how much a child understands as testing is very difficult.
- A motor disabled child may have difficulties to show his communicative competence
- It's necessary to look at the functional ability in different situations and areas.

CONCLUSIONS

Even the non-speaking, profoundly mentally retarded children have a communication. Their communication is non-verbal and they interact in their own ways and sometimes need help to make themselves understood. Some of the children recognize their names, others do not.

There are basic human needs influencing and directing the communication of these children. Parents, as well as teachers, often try to adjust their communication to the child. The adults' adjustment in interaction with children is mostly automatic and unconscious. Although the ability to interact is innate, it' s necessary that the child gets opportunities to interact in order to develop and learn to communicate.

Finally, I feel that it is imperative that the child spends his time with obsservant and sensitive people in a favourable social environment.

REFERENCES

Brodin, J (1985) Probleminventering om gravt utvecklingsstörda flerhandikappade barns leksituation, Pedagogiska institutionen, Stock- holms Universitet.

Brodin, J (1987) Föräldraintervjuer om utvecklingsstörda flerhandi- kappade barns kommunikation, Pedagogiska institutionen, Stockholms Universitet.

Brodin, J (1989) Ett gravt flerhandikappat barns kommunikation. Utprövning av en analysmodell, Pedagogiska institutionen, Stockholms Universitet.

Holmlund, C (1985) Den tidiga kommunikationens betydelse för språkförmågan. En longitudinell studie av ett barns intentionella och imitativa handlingar i kommunikation med omvärlden, Pedagogiska Institutionen, Stockholms Universitet

Kylén, G (1981) Intellectual and Intellectual Handicaps, The Swedish Handicap Institute, Stockholm

Kylén et al (1983) Icke-verbal kommunikation hos begåvningshandi- kappade, Fortbildningen, Göteborgs Universitet

Light, J; Collier, B; and Parnes, P (1985) Communicative interaction between young nonspeaking physically disabled children and their primary caregivers: Part I - Discourse Patterns, AAC Augmentative and Alternative Communication, Hugh MacMillan Medical Centre, Toronto

Nielsen, L (1988) Spatial Relations in Congenitally Blind Infants, Raefsnaesskolen, Kalundborg, Denmark

Patton, M Q (1980) Qualitative Evaluation Methods, SAGE Publications, London

Trevarthen, C (1988) Infants trying to talk. In Söderbergh (Ed) Childrens creative communication, Lund University Press